Executive Summary

At the direction of Governor Frank O'Bannon, the Indiana Family and Social Services Administration has aggressively pursued reform for all of the at-risk populations for which it provides services. Despite this level of effort, Indiana continues to lag behind the rest of the country in providing a comprehensive array of long-term care services that includes not only the traditional health care service settings, but also affordable housing and sufficient in-home and community-based service options. This array of services is critical for facilitating consumer choice and independence, and promoting quality of care and quality of life for Hoosiers who are at risk for, or already in need of, long-term care services.

Persons who utilize long-term care services (regardless of funding source) include: the frail elderly; adults and children with physical disabilities; adults and children with developmental disabilities; adults and children with mental illness; and children and their families who are at risk of involvement in the child protective system, the juvenile justice system, or through academic failure in the education system.

There continue to exist a number of significant obstacles that make reform of Indiana's long-term care service delivery system in Indiana so difficult to accomplish. Namely, affordable housing and community care services are extremely limited, making true consumer choice generally unavailable. Similarly, services and funding opportunities for children who are seriously emotionally disturbed or who are considered to be at risk of abuse, neglect, delinquency, developmental delay, developmental disability or academic failure in Indiana are not available or are not managed consistently in each of Indiana's 92 counties.

To increase the momentum for expanding community capacity and consumer choice, the Indiana Family and Social Services Administration, in an unprecedented effort, has teamed up with the U.S. Department of Health and Human Services to pursue innovation and lasting change. Three federal grants, developed in response to the landmark disability decision, *Olmstead v. L.C.*, have been sought, and subsequently awarded, to assist Indiana in once-and-for-all overcoming the long-standing barriers that have made reform so elusive.

The three grants are as follows:

- *Real Systems Change Grant*. The purpose of this grant is to: establish a Commission that will provide a constant forum for interaction with consumers of long-term care services and their advocates; identify best practices and barriers to community integration and consumer control; provide oversight and monitoring; assist in the implementation of a series of mini-grants to local communities; and make further recommendations for policy and funding actions.

- *Nursing Home Transitions Grant.* The purpose of this grant is to: develop models for diversion from, and transition and of nursing home residents back into the community; provide training, education, and outreach; collaborate with nursing home associations, housing partners, assisted living facilities, and community stakeholders; develop a team to design and facilitate the transition process; identify and select candidates to be transitioned and/or diverted; and evaluate and prepare reports.

- *Community Personal Assistance Services and Supports (CPASS) Grant.* The purpose of this grant is to: provide outreach and information about consumer-directed care services; develop

a consumer-directed personal assistance services model and the supporting infrastructure; establish a fiscal intermediary structure for the attendant care workers; provide enhanced training; develop quality assurance, conflict resolution, and emergency assistance protocols; and develop a system for outcomes-based reporting.

At the lead in this effort, is the appointment by Governor O'Bannon of a bi-partisan, broad-based Commission, representing experts in fields that have never before been convened, to direct and coordinate the elements of long-term care in Indiana that have long been disconnected.

The Commission is funded primarily by the Real Systems Change Grant, but also receives funds from the Nursing Home Transitions and Community Personal Assistance Services and Supports grants for its role in coordinating all three initiatives; it uses no state funds.

The Commission's primary purpose is to develop short and long-term strategies to create or expand community options for persons at risk of being institutionalized, or for those currently in a nursing home or other institutional setting within Indiana's long-term care service delivery system. Its specific functions include: identification of the policy issues surrounding institutionalization; compilation of key statistics and other resource materials; identification of successful and innovative programs that break traditional housing and service barriers; solicitation of consumer perspective; and development of funding and policy strategies. Its work is intended to complement, and not duplicate, the valuable work already accomplished by so many others. It is scheduled to meet monthly for a twelve to eighteen month period, and produce both an interim and a final report for the Governor.

The Commission has convened five special task forces that are devoted to specific policy areas of concern, and a Consumer Advisory Committee specifically designed to research and evaluate the relevant policy issues, advise the Commission, and increase the scope and substance of Hoosier participation in formulating the solutions needed to break new ground in Indiana.

The Commission is also working with the Indiana Family and Social Services Administration to develop and award a number of mini-grants funded through the Real Systems Change Grant. These mini-grants are designed to create community partnerships, provide incentives for public/private partnerships, and serve to encourage innovation at the community level between community stakeholders.

The mini-grants are directed to the three major goals of the Commission:

- To develop community capacity in the areas of community living arrangements, affordable housing, transportation, supported employment, and caregiver support.
- To develop systems that support consumer choice and consumer-directed care.
- To develop innovative systems that help to identify and propose solutions to eliminate barriers to service.

By the Commission's third meeting in September 2002, it became clear that the original assignments and time-lines established for both the Commission and its task forces were not responsive enough to the urgency of many of the system problems and the opportunities presented by the upcoming legislative session. As a result, the Commission decided to deviate from its original workplan and instead refocus the task forces on identifying the most significant of the long-term care service delivery barriers and to develop comprehensive recommendations in response. Each recommendation that was subsequently developed was then assigned to one of three categories: those that should be implemented quickly and with little or no fiscal impact or

regulatory requirements; those that should be implemented quickly but are accompanied by a fiscal impact and/or regulatory changes; and those that are more complex, costly or otherwise difficult that will take more time to develop and implement.

Despite extremely challenging time-lines, the task forces were able to develop a list of recommendations for each of the three categories. Time constraints required them, the Consumer Advisory Committee, and the Commission to focus their attentions on the recommendations in the first category, those that should be implemented quickly and with little or no fiscal impact or regulatory requirements. The focus of this Interim Report is to highlight sixteen (16) specific recommendations that have been identified and studied. Each has been grouped according to one or more "themes," which include: eligibility; streamlining or maximizing funding; developing provider incentives to increase capacity; consumer education; and consumer choice. They are not presented in priority order, but instead are considered collectively to be critical to the overall reform needed to develop community capacity in Indiana.

Another nineteen (19) recommendations have been identified and are scheduled for deliberation and analysis over the next six months. The Commission will continue to work through the five task forces and the Consumer Advisory Committee on their development. Once evaluated they will be presented formally for the Governor's consideration in the final report due in June 2003.

The Commission strongly advises the Governor and the legislature to take action on the recommendations. Each is critical in achieving the long-term care reform that has so long been envisioned by the Governor and so many others, and each is relativity simple to implement.

For the remainder of its appointment, the Commission will work with the Indiana Family and Social Services Administration to fully develop the additional recommendations that have been identified, oversee the mini-grant award process, develop focus groups, consider additional expert testimony, identify and document "best practices", fully develop a long-term care housing and services fact book of statistics and relevant information, develop strategies for capacity building, and define the benchmarks needed to measure change.

The Commission would be remiss if it failed to mention how much work remains to be done. For despite the activity and the level of progress that has been made by the Indiana Family and Social Services Administration and other state and local agencies over the past few years, Indiana continues to remain significantly behind most other states in re-focusing its scarce resources on more desirable, less costly community-based service delivery options. Spending priorities in Indiana continue to focus on institutional care, and progress in resolving many of the more complex service delivery problems such as caregiver support, eliminating process and system barriers, understanding the needs and desires of consumers, and shortage of caregivers, for example, has been frustratingly slow. Furthermore, the common framework for health care that is provided in traditional institutional settings and that favors medically cautious modes of care over one that relies upon consumer independence and freedom of choice continues to be extremely difficult to change. The Commission accepts this current reality but commits itself to being part of the solution.